

PLANNING FOR LONG-TERM CARE

Testimony of

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To The

U. S. HOUSE OF REPRESENTATIVES  
COMMITTEE ON ENERGY AND COMMERCE  
SUBCOMMITTEE ON HEALTH

2:00 P.M. May 17, 2006  
2123 Rayburn House Office Building

## **Improve and Refine Current Long-Term Care System**

We all agree we must continue to improve and refine the Medicare/Medicaid-based long-term care system we have in place. Many improvements still remain to be made that will be beneficial to older adults, particularly those older adults burdened with the kind of serious chronic conditions that truly require skilled nursing home care and, most particularly, those without the ability to pay.

But we can never “improve” or expand nursing homes enough to make them the preferred choice for most older Americans. Even if we could make nursing homes desirable enough, we can’t build enough new facilities to care for *double* or *triple* the number of seniors who will need long-term care over the next 20-30 years.

## **Develop a Home-Based Long-term Care Alternative**

Baby Boomers increasingly demand that we *change* our system of long-term eldercare from an **institution-centered** method of long-term eldercare to a new **home-centered** system. We will need both:

1. An improved Medicare/Medicaid system of long-term care system for the most chronically-ill, low-income seniors
2. *and* a new alternative, a new home-centered system of long-term eldercare for all Baby Boomers—both those of low-income and those who will be private pay.

The demographics before us demand an alternative long-term care system that helps keep most elders at “home.” Staying at home is what most elders and their families want.

Keeping them at home is the only way we can afford to care for twice as many elders

living decades longer than ever before. And it *can* be done—it may be America’s best solution to the Age Boom of long-lived elders—if we do three things:

1. **Review federal (and all state) home health regulations and de-regulate in-home caregiving; i.e., remove Personal Caregiving from home health regulations.**
2. **Improve the quality and availability of in-home caregiving by developing professionally-trained and certified home caregivers, family members, and a new corps of volunteer caregivers.**
3. **Develop a comprehensive public/private delivery system of personal in-home caregiving that applies all available resources—family, volunteer, private and public—to integrated long-term care delivery.**

#### **Separate Caregiving (Personal Care) from Home Health (Skilled Nursing)**

I am *not* suggesting that we *change* home health regulations. Simply remove in-home caregiving (personal care) from the home health regulations—except when in-home care is prescribed by a physician as a medical necessity (skilled nursing). Right now the home health regulations are unintentionally blocking access to in-home caregivers trained and provided through any reputable agency. How can that be? Current regulations do not differentiate between skilled nursing and personal caregiving under Medicare/Medicaid Home Health regulations--*even when the older adult does not need, qualify for, or receive Medicaid benefits.*

Because we have intermingled in-home personal **Caregiving** with **Home Healthcare (skilled nursing)** nearly all Americans, including the **70** percent of older adults who do *not* qualify for Medicaid benefits, are excluded from access to trained home caregivers from any reputable agency even when they are private pay.

**Just remove in-home PERSONAL caregiving from Home Health regulations—except when prescribed by a physician.** Removing the regulatory barriers to in-home caregiving may be the single most important action you can take to provide better access to better caregivers for most Americans, including the 70% who pay for their own homecare. With this barrier removed, we *can* keep more elders at home for life, at lower costs, with more competition to provide professional in-home caregiving through professional caregiving agencies—both private and non-profit—and alleviate a colossal need.

### **Create A New Group of Professionally-Trained In-home Caregivers**

There is an urgent need for the professional training of family, volunteer, and in-home paid caregivers, usually independent contractors, as well as the need for geriatric management services for families who are overseeing the care of a loved one in the home.

A large, new cadre of independent contract, in-home direct care providers is required to meet this growing need. However, almost none of these care providers have received professional training on how to care for an older adult in the home. Elders are thus very vulnerable to improper care and the family has no way to judge the competence of caregivers in the home setting.

Therefore, there is an urgent need for creating the standards and structure for support of a professionally-trained community of paid in-home caregivers who provide personal care and other non-medical services to older adults in the home and who

understand the behavioral problems that may be present when caring for an older adults with a dementing or other chronic disease.

There are many barriers to the professional in-home caregiving many families need:

- **Currently, there are no caregiver training requirements for independent contractors working as in-home paid caregivers.** There are no standards for training and no structure in place today to support independent contractors working as in-home paid caregivers. There is no well-organized national organization or association that supports this evolving cadre of direct care providers to help establish caregiving as a career.
- **There *are* caregiver training requirements set by Medicare/Medicaid regulations for personal care and home health aides working for home health agencies.** However, only elders who require skilled nursing care can qualify for personal care provided by a home health agency. Such personal care must be prescribed by a physician and is available on a limited basis--not 24/7 for extended periods of time--as some families need. This is *not* long-term care. Families cannot simply request personal care services provided by a home health agency.
- **Nearly all families must contract privately with individual caregivers--and they must find them on their own. Most of the caregivers they find are untrained.** Families sometimes receive lists of potential in-home caregivers from hospitals or health care agencies. Sometimes they learn about potential caregivers by referral or through advertising. Many of the caregivers

found through these means have a heart-to-serve, but they have no formal training and limited knowledge about caring for older adults in the home.

- **In-home caregiving is not considered a career path.** Caregiving is generally viewed as minimum wage work. Currently there is no way for them to receive benefits, be bonded, receive further training and continuing education, etc. They are typically among the medically uninsured, a real problem in our health care system today.
- **As an independent contractor, the case load for an in-home caregiver varies and may not provide regular work;** therefore, many in-home caregivers leave the field and seek other employment that is often more stable, better-paid, and may even include benefits. This environment results in families often finding it very difficult to find and keep in-home paid caregivers when needed.
- **For-profit companies do exist that provide non-medical caregiving to older adults in the home, but few such companies exist that also can and do provide the physical and behavioral care that is often needed to care for older adults with dementia or other chronic, debilitating conditions.** Many of the private companies require little or no training for the caregivers they hire. When physical care is needed, most states have outdated regulations prohibiting any organization except a home health agency from providing that care. But if the older adult doesn't require skilled nursing care, they can't get the caregiving help they need to stay at home from *any* organization.

We must break with the past and find new ways to create a community of professionally-trained home caregivers--a community with the shared standards and structure needed to grow a large cadre of competent, compassionate, professionally-trained in-home caregivers. We suggest that we

- **Develop and implement national standards for the education and training of in-home paid caregivers.**
- **Create a national organization/association for the new generation of professionally-trained in-home caregivers, most of whom are independent contractors.** The organization will oversee the accreditation process of curricula used to train this cadre of caregivers, the certification/licensing process, the continuing education requirements to maintain certification, provide opportunities for group rates on medical and dental insurance, bonding, etc. Family members needing in-home paid caregivers will then be assured that a caregiver certified by the organization has been professionally-trained in home caregiving skills, tested for competency, and is continuing to add new caregiving knowledge.
- **Establish new in-home caregiving quality standards so that all third party payers, including CMS, require that all in-home caregivers must be members in good standing in the national professional home caregiver certification organization to qualify for reimbursement.** All agencies or companies providing in-home caregiver services for a fee to families must meet the same membership, training, continuing education, and quality standards for their employees.
- **Allow, encourage, and incentivize a new type of in-home caregiver staffing agency to provide families with caregivers who are professionally-trained in the physical care and non-medical care of an older adult and who understand the behavioral issues that might arise.** Keeping the cost of caregivers placed through these agencies at an affordable level, while paying the caregivers a reasonable wage and benefits, would provide professional caregivers with career stability and provide families that need paid caregiving for a loved one with a reliable source for trained caregivers.

Again, all in-home caregiving recommendations depend on the removal of federal and state regulatory roadblocks to professional in-home caregiving and geriatric care management. In-home caregiving must be re-defined to separate it from “home health”

care (skilled nursing) and its restrictions. Caregiving is *not* “health care” and should not be regulated as is medical care.

**Develop a Comprehensive Public/Private Delivery System for Home-based Long-term Care.**

With regulatory barriers removed and with a program for providing professionally-trained and certified home caregivers (including family, volunteer, and paid) is operational, there will still be a major issue of connecting older adults and their families with the resources they need to stay at home for life.

A model has been developed for a comprehensive, integrative delivery system combining public and private resources. It provides one-stop, one-call access to a community-based system of eldercare that provides information, referrals, and consultation to older adults and their families. The tool kit can be adapted as a private business, a non-profit service, a community-based service, a faith-based initiative and more.

It requires only the freedom from regulation so that the needed services can be delivered. There is great interest in pursuing this model at the community level and I believe this is the direction elder caregiving will develop over the next decade. It is flexible, fundable, affordable, and compassionate. (See Exhibit 1: “Community & Faith-based Model to Help Older Adults Stay at Home For Life”)

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# Community & Faith-Based Model to Help ElderStay@home™ Older Adults Stay At Home for Life

Elder HelpCare Management  
FOR ELDERS & THEIR FAMILIES

## Certified Professional Home Caregivers

- Professional Caregiver Training
- Security Checked
- Referral Service and Directory

## Family Home Caregivers

- Training & Workshops
- Support & Respite

## Community & Church-Based Volunteer Home Caregivers

- Professionally Trained
- Home & Respite Care
- Adult Day Care
- Donations Optional
- Rural CareCircles

## ONE•STOP • NWA HelpCare • ONE•CALL

*First contact with elders and/or their families to help them negotiate the Age Maze.  
Brief telephone/in-person intake for database, follow-up, and evaluation*

- Information
- Referral
- Consultation

## Information

- Other Eldercare Resources
- Aging Education Resources
- Home Caregiver Directory

## Referral

- Suggest AAA/Medicaid/Other
- Home Caregiver Referral Network
- Volunteer Caregiver Referral Network
- Family/Elder Counseling

## Consultation

- Free Consult (1 Hr.)
- Further consultation/counseling
- In-home assessment (3-Hrs.)
- Care Plan (2-Hrs.)

## • Home Health

## • Hospice

## House Calls

- Geriatricians
- A.P.N.

## Counseling

- Mental & Behavioral Health

## Geriatric Care Management

- Assessments & Care Plans
- Continuing Care Mgt. Services
- Local/Long Distance Support
- Referrals--Professional/home